Information Systems & Technology

***P**roject **C**harter*
***F**or*
***N**ational **E**lectronic **D**isease **S**urveillance **S**ystem (NEDSS)*

Version: **1.2**
Date: 13 July 2001

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Promote Prevent Protect
Utah Department of Health

Project Charter

***F**or*
***N**ational **E**lectronic **D**isease **S**urveillance **S**ystem (NEDSS)*

This Project Charter Document for the National Electronic Disease Surveillance System (NEDSS), describes intent, scope, organization, and the general proposed plan for accomplishment as approved by the NEDSS Executive Committee:

_____
Charles D. Brokopp, Dr.P.H.
Director of DELS
Chairman

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Robert T. Rolfs, M.D., M.P.H.
Director of Centers of Health Data
Member

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Barry E. Nangle, Ph.D.
Director of Bureau Vital Records
And Statistics
Member

_____
Rhoda M. Nicolas, M.B.A.
UDOH Chief Information Officer
Member

_____
Date

General Notes about the Project Charter:

This section is explanatory only and is not part of a typical project charter.

A project charter is essentially a contract between the project manager on the one hand and the project sponsor and stakeholders on the other. While having no legal consequence, an agreed-upon charter nevertheless represents a formal commitment between these parties. Writing, maintaining, and using an effective project charter is one of a project manager's most important jobs.When properly used, a charter will be the single most important tool the project manager possesses for managing the expectations of the project sponsor and all other stakeholders. When formally agreed to, the charter establishes the very foundation of the project. When key elements in the project change which compromise the agreement as established in the charter, (e.g., a significant change in scope or the invalidation of one of the primary assumptions about the project), then the project charter must be updated to reflect these changes and these changes approved. This is in essence a re-negotiation of the contract.A good project charter is not necessarily lengthy, although it can be. Most importantly, it answers basic questions about the project as clearly and succinctly as possible. An appropriate length is simply the length required to establish an adequate contract for doing the project. In general, you'll find that shorter is better.

The rest of this document consists of an outline of possible sections of a project charter. The actual sections in your project charter are up to you. Think it through before you add or delete sections!

1. Executive Summary

1.1 Project Purpose:

The purpose of this project is to design, develop and deploy an integrated public health surveillance system that will sequentially replace existing stand-alone public health surveillance systems, support core public health surveillance activities, support notification and reporting, expand surveillance information accessibility, and will have the flexibility to support some non-surveillance business processes. The system developed in this project will be secure, web-enabled, client-focused, and standards-based. The first priority will be the communicable disease systems here defined as diseases listed in the communicable disease rule.

1.2 History:

For the past few years, public health surveillance within the Utah Department Of Health (UDOH) and Local Health Departments (LHDs) has utilized a variety of independently developed software systems, such as National Electronic Telecommunications Systems for Surveillance (NETSS), HIV/AIDS Surveillance Report (HARS), Tuberculosis Information Management System (TIMS), and Sexually Transmitted Disease-Management Information System (STD-MIS) (See section 4.4) for the communicable diseases. Many of these systems are built on the DOS platform and are subject to the limitations inherent in DOS-based systems. These systems were originally designed as program specific data collection and reporting tools. They have limitations on their data analysis capacity and lack the structure or functionality necessary for surveillance system integration.

The Center for Disease Control and Prevention (CDC) recognizes a need for a new type of electronic surveillance infrastructure that takes advantage of current information technology and supports integration and streamlining of surveillance practices. In 1999, the CDC proposed the development of the NEDSS in partnership with public health partners and state and local health departments. In May 2000, the Surveillance Program (SP) within the Bureau of Epidemiology (BOE) applied for and received funding for two categories of the NEDSS development process. The first was an assessment and planning award. Within this category, the SP proposed to 1) assess the IT capacity of Utah's medical and public health community, and 2) develop a plan to migrate into the NEDSS architecture. The second category provided funding for the SP to develop an integrated data repository (IDR). This IDR will result from several layers of database modeling. These awards provided the following resources:

Assessment and Planning	NEDSS Project Coordinator	$64,000
	Contract Assistance	$20,000
IDR Development	Community Health Technician	$35,000
	Contract Assistance	$100,000
	Direct Assistance	$15,000

1.3 New System Vision:

The NEDSS system will allow two types of data entry. Data can either be entered through an online reporting form for those users (e.g. local health departments and health care providers) who are not using other case tracking systems. Data can also be accepted as standardized batch files of records, using the HL7 messaging system, for those users who produce large volumes of reportable data (e.g. laboratories, hospitals, and health care organizations) and use another case tracking system (e.g. the laboratory database system). Other states receiving reports of cases belonging to Utah could forward those records through a standardized messaging system (HL7/XML). Data provided to the system will go into a holding file (as either a separate set of tables, or with flag fields, or some other method) pending review and approval.

The review process will be conducted by SP staff and LHDs. The review will include validating data, validating data providers, screening for duplicate reports, matching clients with previous (other disease events) reports, assigning to case management, and other activities. This process will result in final approval and integration of the data into the IDR. Local health departments will be able to review, in real time, line lists of filtered (i.e. by event type, etc) data that belong to their jurisdiction. Other data users (e.g. health care, other UDOH offices, and the public) will be able to get real time information dependent on their level of security. For example, a UDOH office may be able to see a line list of cases for which they have specific jurisdiction (e.g. STD program will be able to review cases of sexually transmitted diseases, but would not see the non-STD disease events associated with those clients, and would not be able to see clients with no STD events). The public would be able to review real-time aggregated data and information (e.g. rates by geographic region or time).

The NEDSS system would maintain a directory of public health officials and the level of authorization for viewing data associated with each public health official. Overlaying the data entry, data management, and information presentation processes would be rules of security that conformed to all the legal requirements (e.g. state and federal laws), to ensure that the data was quality controlled and protected. Summary data would be reported to CDC. This process could be activated by SP staff using a standardized reporting system (XML). If possible, CDC may be able to activate that reporting capacity through a secure query system for which only authorized CDC agencies would have access. Cases of disease reported to UDOH belonging to other state jurisdictions would be forwarded to those state health agencies through a standardized (HL7/XML) messaging system.

Information presentation will include the ability for the user to conduct summary queries of data and to have that information presented in a variety of formats including tables, graphs, and maps using standard epidemiological formats. The system will be intuitive for users familiar with web-based applications. In addition, the NEDSS system will include tables of descriptions accessible by users to assist with data entry and data query. Those tables will include such things as case definitions, definitions of case status, procedures for interpreting analytical results, etc.

Initially the NEDSS system will support surveillance of communicable diseases and the STDs. The system will have the flexibility to support other surveillance requirements with minimal modification and personnel training. The NEDSS will allow for independent IDR and module upgrades without affecting the operation of other modules, with minimal maintenance to the linkages between the IDR and the modules. The modules may be physically stored on a variety of locations. For example, the IDR could be implemented on the state mainframe computer, while the web applications for security, data entry, management, analysis and presentation may be implemented on a UDOH server or on the Health Alert Network (HAN) server. The system will be designed so that upgrades can be implemented from the SP offices and certain SP staff will have appropriate rights to maintain and upgrade modules.

The SP and other specified users would have the ability to conduct specialized trend analysis (e.g. ARIMAs and other temporal trends on specific geographic and demographic populations for specified disease events). Finally the SP will have the ability to access the data in the IDR either by exporting it to another format or by use of a query system to conduct specialized data analysis (such as cluster trends) as the need arises.

1.4 Objectives:

The overall long-range objective of this project is to sequentially replace and integrate existing stand-alone public health surveillance systems with a modern system (the NEDSS system) that simplifies public health surveillance processes, and adds additional functionality nonexistent within the current systems. Short-term objectives supporting the long term are to develop a business process model of public health surveillance and Epidemiology, evaluate the Internet connectivity of public health, hospitals, and laboratories, and develop an IDR. This charter document addresses the plans for accomplishing the short-term goals. Initially those objectives will focus on a few closely related surveillance systems. On successful integration of the first small group of systems, other existing surveillance systems will be integrated in a prioritized sequence following the plan (See Appendix A).

1.5 Costs/Benefits:

At this stage of the project a full cost/benefits analysis has not been performed. However, we anticipate that the NEDSS will require additional funding and effort, through development and implementation. Upon completion, NEDSS will result in considerable monetary savings and personnel time. The project received initial funding for planning and development from CDC, however, this project will likely require additional funds to be covered by the department. In addition, initial implementation and validation will result in an increased workload through the validation time period, as surveillance will be conducted using both existing systems and the new NEDSS in parallel. Other costs may include:

- Transition of some jobs, particularly data entry personnel.
- Loss of some of the flexibility of the data structure for ad-hoc studies.
- Loss of some of the currently available system functionality.
- A requirement to develop mechanisms to migrate data into the new system.
- Disruptions of current system and business practices.

- A requirement to develop mechanisms to support data requirements for non-integrated functionality of replaced systems, for example case management.
- A requirement to develop data controls, quality assurance protocols and security measures for a centralized, versus the current decentralized, surveillance system.
- Training requirements (time and money).

Benefits will include streamlining disease data collection, analysis, reporting and notification. Streamlined procedures will result in significant improvement in the public health response and intervention to disease outbreaks, more responsive processing or information needs, and improved public health policy-making. In addition, this project will result in significant savings in staff time. This time can then be used for other public health activities. Other benefits include:

- More timely reporting and availability of surveillance data.
- Feedback to data providers.
- Improved access to data.
- Improved efficiency of system maintenance (as opposed to multiple different software systems used presently).
- Improved documentation and shared understanding of business processes used for surveillance.

2. Scope

2.1 Inclusions:

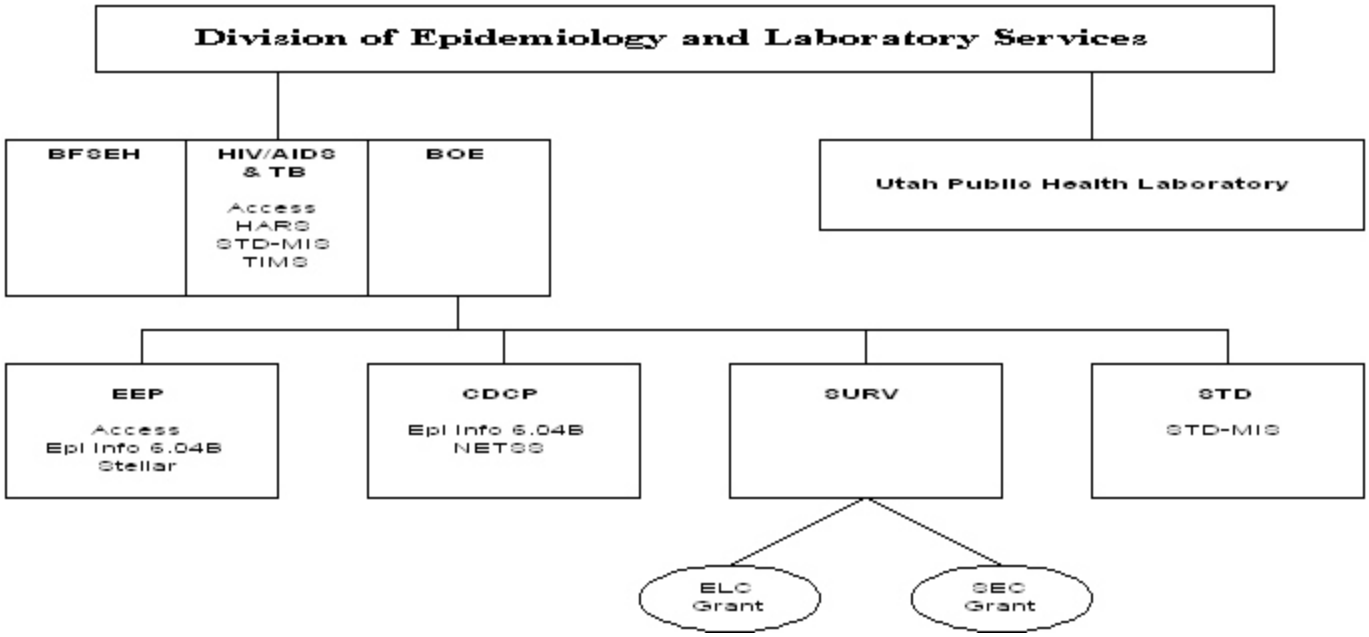
In the long term, the scope of this project is:

1. To develop a business process model for the surveillance functions carried out at the state and local levels for communicable disease surveillance (HIV/AIDS, STD, TB and other communicable diseases as defined by the communicable disease rule). The first integration priority for this project will be to integrate the Communicable Disease Program (NETSS) and STD Program (STD-MIS) surveillance systems currently used by the DELS and local health departments, starting with those maintained within the BOE and/or the bureau of HIV/AIDS that are associated with communicable disease reporting. Following successful integration of those systems, the project will be expanded to more diverse ongoing systems (chronic diseases, injuries, cancer, adult and child lead poisoning, etc.) and then possibly followed by specialized or temporary surveillance projects (asthma, work-related burns, etc.)

2. To develop an IDR that can support the surveillance functions for those programs and eventually more general surveillance functions in the UDOH, including, for example, injury, chronic diseases, and maternal and child health.

The NEDSS project will impact any person or organization that either provides or uses Utah's public health data or information. Those include clinicians, laboratories, hospitals, health care organizations, local health departments, public health policy makers, the public, and others. This project will impact all currently supported surveillance activities within UDOH. (See Appendix A)

The figure below represents the current organization of the Division of Epidemiology and Laboratory Services (DELS) and shows the relationships of the various programs that will be impacted by the NEDSS project. Concurrent with the NEDSS development are some DELS reorganization.



Key
Access - Microsoft Access
BFSEH - Bureau of Food Safety and Environmental Health
BOE - Bureau of Epidemiology
CDCP - Communicable Disease Control Program
EEP - Environmental Epidemiology Program
ELC - Epidemiology and Laboratory Capacity
HARS - HIV/AIDS Reporting System
HIV/AIDS & TB - Bureau of HIV/AIDS, TB and Refugee Health
NETSS - National Telecommunication Systems for Surveillance
SEC - Surveillance and Epidemiology Capacity
STD-MIS - Sexually Transmitted Diseases Management Information Systems
STD - Sexually Transmitted Diseases Program
SURV - Surveillance Program
TIMS - Tuberculosis Information Management System

Figure 1-1 BOE Surveillance Programs and their Information Systems

Included functions or activities will be:

- Data (case and disease) collection functions and methodology.
- Case detection through the collection of reported health data.
- Case verification (establishing that a report is a new case of an included event collected by the system).
- Data quality assurance and completeness.
- Routine case investigation data (information collected on most or all cases).
- Analysis of patterns including such things as calculation of rates, analyses of trends, assessment of risks and patterns by person, place and time.
- Routine notification and messaging functions.
- Data security.

2.1.a Information Systems to be Replaced:

Eventually, all public health surveillance systems operated in the UDOH will be integrated into or replaced by the NEDSS system. Initial priority will be to replace a few closely related systems in DELS such as the NETSS system and STD-MIS system. Upon successful completion of this integration, the process will be continued to include more diversified systems (See Appendix A).

2.1.b Existing or Potential Surveillance Data Sources:

Currently data is collected under disease and injury reporting rules promulgated by the UDOH (See appendix C). Additional data sources will be integrated into this project. Those data sources include:

- Reportable disease and injury reports from the medical community.
- Laboratory results.
- Medical examiner's data.
- Death Certificates.
- Birth Certificates.
- Hospital admissions or discharge data.
- Emergency room data.
- Diagnostic information in billing data (Such as UHIN).

2.1.c Users:

The NEDSS system will be developed to support the information needs of the following users:

- State public health.
- State public health policy makers.
- Local public health (See Appendix B for map).
- Local public health policy makers.
- Federal public health such as CDC.
- The interested public.

2.1.d Locations:

The NEDSS system development will include the following locations:

- The BOE.
- Hospitals and clinics.
- Private health care providers.
- Laboratories throughout the state and the nation.
- LHD (See Appendix B for map of location).
- CDC.
- The Office of Information Technology Services (ITS).

2.2 Exclusions:

The NEDSS project will not initially include non-surveillance related public health data or functions such as:

- Case Management.
- Partner Notification.
- Treatment tracking.
- Outbreak investigations involving special questionnaires.
- Outbreak investigations involving control group comparisons.
- Tracking or noting of clinical services provided by programs.
- Financial matters relating to care.
- Advanced statistical analysis or modeling tools.
- Public access to identifier-data.

2.2.a Information systems that will not be replaced:

The WIC and Medicaid surveillance data have special constraints that will prohibit inclusion in the NEDSS project in the near future. In addition, specialized surveillance projects such as emergency room or other syndromic surveillance systems will be developed independent of the NEDSS and will not be included.

2.2.b Data sources that will not be included:

In addition, outcome-specific health data collected by the department to conduct surveillance and epidemiology activities will not be included, such as:

- Facility (such as food services facilities or recreational facilities) inspection results.
- Routine negative screening results.
- Service enrollment data.
- Syndromes.

3. Project Resources

3.1 Project Staff:

1) Abdoul Shmohamed is a Community Health Specialist in the SP. Abdoul will be responsible for coordinating the business aspects of the NEDSS project and overseeing the day-to-day activities of the project as the NEDSS coordinator. Abdoul will serve as the principle daily contact.

2) David Jackson is a staff Epidemiologist in the SP and the ELC Project Coordinator. David is responsible for integrating all the public health surveillance activities being conducted within the bureau. He will supervise the NEDSS project.

3) Brent Neal is an Information Technician/Program Analyst in the SP. Brent will be responsible for coordinating the technical aspects of the NEDSS project.

4) Melissa Carbine is a Community Health Technician in the SP responsible for providing clerical support and will be responsible for the IT capacity survey.

5) Sam LeFevre is the SP Manager in the BOE and is the principal investigator of the ELC and BT grant projects including the development of the NEDSS. Sam is experienced in surveillance epidemiology and has some technical experience in programming.

3.2 NEDSS Executive Committee:

The NEDSS project has the potential to impact many UDOH programs and projects. Therefore, it is necessary to have an Executive Committee that will ensure that the NEDSS project conforms to the UDOH and State IT framework and vision. The Executive Committee will be responsible for 1) providing department level decisions as required 2) providing oversight and guidance on work priority, scope, and policy for the NEDSS project, and 3) ensuring UDOH acceptance of the NEDSS product. The committee shall meet as often as needed. We propose that the following persons be assigned to the NEDSS Executive Committee:

Dr. Charles Brokopp, DELS, Chairperson
Dr. Robert Rolfs, CHD, Vice Chairperson
Dr. Barry Nangle, VR, Member
Rhoda Nicholas, CIO, Member
Dr. Evan Nelson, LHO, Member
Sam LeFevre, SP, NEDSS Staff Liaison

3.3 NEDSS Policy Workgroup:

In the process of developing the NEDSS, decisions will need to be made about the content that will best meet the needs of all of the business partners. Therefore, we propose a policy workgroup:

1. Identify what business processes to be included.

2. Identify what analytical methods to be employed.

3. Develop proposals and other alternative courses of action for the NEDSS Executive Committee.

In addition, this workgroup will serve as the subject matter experts for content, process and data matters relating to the NEDSS development. The Policy workgroup will need to have expertise in health department policy, surveillance and epidemiology and have an understanding of information needs of surveillance information users. This policy workgroup shall meet at least once a month to provide oversight and direction. We propose the following organization for this Workgroup:

UDOH-CD	TBD
UDOH-non-CD	TBD
DELS	Teresa Garrett
LHD Epidemiologist	Ilene Risk or SLVHD staff member
LHO	TBD
Laboratory	TBD
Provider (IHC)	Jim Alred
UofU DFPM	Steve Alder
ID Physician	Andy Pavia
NEDSS Staff Liaison	David Jackson
UDOH Epidemiologist	Injury Epidemiology
UHIN	TBD

3.4 NEDSS Technical Workgroup:

The objective of this workgroup is to identify the technology needs for the NEDSS. In the process of developing the NEDSS, decisions will need to be made about technology (commercial-off-the-shelf software, data security, data and system standards, data modeling) that best facilitates the objectives of the project. Therefore, we propose a technical workgroup:

1. To identify and describe those needs.
2. To identify, develop and propose alternatives to meet those needs to the NEDSS Executive Committee and the Policy workgroup.

In addition, this workgroup will serve as the subject matter experts for software and hardware, standards and security matters relating to the NEDSS development. The technical workgroup will need to have expertise in information systems, information security, Oracle, data modeling, data retrieval, web-based systems design, messaging, and data standards. This workgroup shall start to meet upon the completion of the business process development and should arrange to meet as often as needed. We propose the following organization for this Workgroup:

OIT	TBD
ITS	Robert Woolleey, Asst. Dir. ITS 538-1072
UDOH (USIIS)	TBD
UDOH (IBIS)	TBD
LHD IT	TBD
HL7	Stan Huff or representative
CDC Liaison	TBD
UHIN	TBD
NEDSS Staff Liaison	Abdoul Shmohamed

3.5 UDOH and ITS Personnel Resources:

1) Don Gabriele is the technical development manager for the CHARM project who has expertise in the development of data models.

2) Dean Zumbrunnen is the manager of the Database/CICS/Application Support Service (538-3235) at ITS. Dean has been contacted by the NEDSS Team to determine his availability. His office has several personnel (DBA) working in the service that will implement the physical IDR on the state mainframe and will provide maintenance to the IDR.

3) Kerry Huntington is the manager of Web Application Development Section (537-9045) at ITS. Kerry has several personnel working in the section that will assist the NEDSS staff in implementing web applications supporting the IDR.

3.6 Contractor Resources:

The NEDSS grant was awarded $120,000 for contracted services. These funds were allocated as $20,000 to assist with the Assessment and Planning component, and $100,000 to assist with the development of the IDR.

4. Assumptions and Constraints

NEDSS is broad, multi-year initiative. To develop and implement it will require a considerable investment of resources. This project will be completed in a series of phases. The work progress and eventual success of the NEDSS project is dependent on the following assumptions.

4.1 Assumptions and Constraints:

4.1.a Assumptions

1. CDC will be able to provide continuous funding support for this project.

2. The UDOH Executive Director and Executive Director's Office supports the NEDSS project.

3. Concurrent reorganization of the UDOH disease surveillance capacity will improve the ability to integrate divergent surveillance systems.

4. Concurrent UDOH information integration efforts (such as Charm, and IBIS) will complement the NEDSS project and strengthen the ability of UDOH to acquire federal funding.

5. The NEDSS project will be able to leverage the activities and developments of other states involved in the national NEDSS development project.

6. CDC will continue to develop and provide useable standards for information, software and hardware.

7. The LHDs will support the development and implementation of NEDSS.

4.1.b Constraints:

In addition to the above assumptions, there are several known constraints that the NEDSS products will have to be compliance in order to be successfully completed and implemented. Those constraints are:

1. NEDSS will have to be developed based on CDC defined specifications and standards, thus limiting the flexibility of state-developed NEDSS architecture.

2. The CDC funding is provided with a communicable disease surveillance priority. The NEDSS system will first need to integrate those systems.

3. NEDSS will have to comply with the national messaging standards, such as XML, HL7, etc.

4. There are timelines and phases under which certain deliverables must be met for the NEDSS grant, in order to insure continued funding.

5. The state and local health departments have promulgated rules, policies and standards, such as reporting times, methodology, and data that will need to be supported.

6. The UDOH is currently working on other integration initiatives that will need to be supported.

7. Disease surveillance and public health response will need to continue through all phases of development and implementation. There can be no break in services.

8. The LHD have very limited additional resources (funds, hardware, software and personnel) to provide to the development and implementation of the NEDSS.

4.2 Critical Success Factors:

4.2.a Overall Critical Success Factors:

The overall long-range critical success factors necessary for successful implementation of the NEDSS project are:

1. Successful development of a strategic plan.

2. Successful implementation of the IDR.

3. Successful acquisition of other NEDSS modules such as the Data Entry-Data Management Module.

4. An accurate understanding of the information needs of the data users.

5. Successful acquisition of additional funds necessary to fully develop and implement modules.

4.2.b Short-Term Critical Success Factors:

The short-term critical success factors necessary for successful assessment, planning and development of an IDR:

1. Successful organization of an effective team and workgroups.

2. Cooperation of the impacted programs.

3. Effectiveness of the process used to identify and document program business.

4. Effectiveness of the process used to reverse engineer targeted software programs.

5. Publishing of a comprehensive and accurate strategic plan.

6. Successful identification of a knowledgeable contractor to conduct the data modeling.

4.3 Risks / Exposures:

1) The NEDSS is dependent on access to resources within the state ITS and accessibility by the local and state health departments and the public health and medical community. Current estimates are that only 59% of local health department employees have access to the Internet (however, those that have a need to access surveillance data is probably higher, but not 100%). Lack of access will limit the ability of users to take advantage of the functionality of this system. However, IT capacity is continually improving through the efforts of the Health Alert Network (HAN). The NEDSS project will work closely with the HAN team to ensure that HAN IT capacity building efforts will support the NEDSS project.

2) The NEDSS architecture is dependent on continued development funding from the CDC. Loss of this funding without replacement support from the state, or other sources will result in the incomplete implementation of this project. Management and mitigation of this risk will require the achievement of scheduled deliverables. This may require executive level intervention to remove barriers to achievement of those deliverables.

3) The NEDSS system is dependent on a significant technical understanding and expertise. Currently, the SP does not have technical expertise in the area of information technology and database development. If the SP is unable to access department, state or private contractual expertise, the system will not develop with the best possible technologies. The NEDSS team will avail themselves to opportunities to gain some technical understanding, however, significant expertise will need to be obtained through contracting.

4) Many of the current systems include non-surveillance related functionality (e.g. case management). The proposed NEDSS project will mainly focus on surveillance functions, but could include other functionalities. The impact on program operations with the implementation of the NEDSS will need to effectively address the additional functions performed by existing systems of which NEDSS will replace. The NEDSS team will need to work with the managers of those systems to identify possible alternatives for overcoming this obstacle and ensuring buy-in during the transition phase, where both systems may need to be operational to cover all services.

4.4 Current System Description:

The UDOH utilizes a variety of software systems to perform some functions of public health surveillance. There are more than 60 databases being used by programs in UDOH. At least a third of these collect public health surveillance data. These systems have a wide range of development philosophies, platforms (DOS, Windows, ASCII, dBase, SAS, Access, etc.) and include a wide range of surveillance functionalities.

4.4.a NETSS

The data system used by the Communicable Disease Program to conduct communicable public health surveillance (excluding STD, TB, and HIV) is the NETSS database and some associated database line lists for hepatitis.

The NETSS database is a DOS-based system that uses a NETSS specific database structure. Typical data acquisition for NETSS is manual entry of reports that are sent to BOE. Even reports that are sent electronically are printed and manually re-entered by the BOE. The NETSS system was designed to send data to CDC where it is incorporated into the National Notifiable Disease Registry. The data is stored in an array of database files, which can be related together in a limited fashion. There is a unique set of files for each year. Analysis of several years worth requires ad-hoc manipulation of the data to create a data set. This data will become obsolete as soon as additional cases are entered. In addition, the analytical functions of the NETSS system are derived from the Epi Info software, which are focused on risk assessment rather than trend analysis. Trend analysis is difficult or requires exporting the data into other, more sophisticated, statistical packages.

The BOE has installed NETSS at most of the local health offices. The process for transferring data from the LHD to UDOH requires the following steps: First, the data is entered into the NETSS system. The data is then exported into a report file. The NETSS system is unable to retain information about what has been previously reported so the user has to keep a log of reported records. The reported file is then encrypted and zipped and emailed to the UDOH. At the UDOH the data is unzipped, decrypted and printed. The printed copies of reports are evaluated and approved by staff epidemiologists. The printed reports are then re-entered into the state's NETSS database. Multiple reports of a single event may result in multiple entries for that event. Individuals with multiple events are entered for each event. No relationship exists for those events. Each day, the BOE prints a line list of reports for each local health department and faxes those line lists to the LHD. The LHDs then conduct investigations on those reported cases, however, may not enter cases reported to the state first into their NETSS system, therefore the local NETSS system data is incomplete for local data analysis. The process often breaks down, requiring the local health departments to make more than one attempt to send data.

4.4.b STD-MIS:

Sexually Transmitted Disease-Management Information System (STD-MIS) is a DOS-based data management system developed by the CDC to provide a generic software application that addresses the most common issues dealing with STD to manage data received from labs, providers, clinics, etc. This program is also used to export information to NETSS and use EpiInfo for data analysis. However, unlike NETSS, STD-MIS allows multiple users to do data entry at one time. This program is mainly used by the UDOH. Some LHD use the STD-MIS on an occasional basis to manage cases. This software package allows the STD program to do full case management, including treatment tracking, interview scheduling and management, contact tracking, and other information needed for surveillance.

4.4.c TIMS:

Tuberculosis Information Management System (TIMS) is program designed to gather tuberculosis (TB) surveillance information and to facilitate treatment, control and elimination of TB from the United States. TIMS is a newly updated computer program that runs Microsoft Windows or NT. TIMS allows the organizational user to combine functions of surveillance and patient management using one single program. This system is easy to use and enables data to be exported to other sophisticated software for analysis.

4.4.d HARS:

HIV/AIDS Surveillance Report (HARS) is a collection of DOS-based computer programs and data files developed by the Division of HIV/AIDS at the CDC which simplifies the management and analysis of HIV and AIDS surveillance data. HARS usage is limited only to UDOH to enter and edit data, generate reports, and improve data accuracy. However much like the NETSS systems, HARS data is fed by manual entry of reports that are sent to the HIV/AIDS program. The HARS report generation and analysis utilizes PRODAS. Trend analysis is difficult to do with this system and requires the data be exported to other statistical software packages.

5. Plan

Throughout each phase, opportunities to leverage work and successes completed by other agencies conducting similar research and development will be explored. It is likely the number of opportunities will increase in the future. Current opportunities include the use of research and development conducted by CDC and other state health departments receiving funding for NEDSS development, concurrent projects within the UDOH such as (IBIS, CHARM and USIIS) as well as within the health care industry such as the UHIN. Work completed by these projects include development of messaging and reporting modules, reverse engineering of common current stand-alone surveillance systems such as NETSS, development of physical data models, and development of security protocols and modules. This type of information is available over the web in a secured CDC WebBoard designed for the NEDSS project and made available to the participating public health partners.
Phases:

5.1.a Phase I: Organization:

5.1.a (a) Approach:

The SP under the direction of the Executive Committee will organize the project team and workgroups described above. The project coordinator will be responsible for:

- Defining roles and responsibilities of each team member and the workgroups.
- Developing a timeline that describes sequential and concurrent activities to be accomplished.
- Oversee the day-to-day activities of the project.
- Identify deficiencies and resources to fill those deficiencies.
- Prepare the RFI for a contractor to conduct the IDR design through development phases.

5.1.a (b) Methodology:

The SP and the project coordinator will organize the Executive Committee, policy workgroup, and the technical workgroup.

5.1.a (c) Deliverables:

1. NEDSS Project Team.
2. NEDSS Policy Workgroup.
3. NEDSS Technical Workgroup.
4. Project Timeline.

5.1.b Phase II: IT Capacity Assessment:

5.1.b (a) Approach:

The IT Capacity of Utah's medical and public health infrastructure will be conducted in three separate projects. The minimum information to be gathered by these assessments is percentage of infrastructure that has Internet access, method and power of access, types of client information software used and reporting policies. Assessment of the local public health activities will be conducted leveraging the NETSS maintenance activities, the HAN capacity development activities, and the DOJ and other similar surveys. Assessment of the hospitals, laboratories and similar facilities will be conducted leveraging the activities of the emergency department syndromic surveillance project and the University of Utah surveillance projects. Additional assessment may be required after evaluation of the data obtained from these activities. Assessment of private physician offices will be conducted using a short mail-in survey. This survey will gather data on type of computer and operating system, connectivity to the Internet, type of client registry software used, and reporting policies. There are approximately 5,000 physicians registered in Utah. Random selections of those physicians will be contacted by mail and invited to complete and return the survey, continuing until at least 500 responses are received.

5.1.b (b) Methodology:

A standardized survey will be developed and mailed to randomly selected physicians until 10 percent of physicians have responded. The most important questions on the survey will be the type of computer used, the type of operating system used, the type of Internet connectivity used. Results of the survey will be analyzed using standard descriptive statistics and a report will be prepared with conclusions on the overall access by physicians to the Internet.

5.1.b (c) Deliverable:

A final report describing the overall Internet connectivity of physician offices.

5.1.c Phase III: Surveillance Business Model:

5.1.c (a) Approach:

Currently within the BOE, there are some epidemiological processes that are not conducted, because the surveillance system either does not support the data required for those processes

or lack the functionality to conduct those processes. There are some surveillance processes that will significantly improve the ability of public health to detect and assess the response to disease outbreaks.

The Project Team will develop a matrix of programs and prioritization criteria based on guidance from the Executive Committee. This matrix will result in a prioritization of programs to be integrated in the NEDSS project. This matrix may be re-evaluated throughout the process. Because the imputes for the NEDSS project is communicable disease, the NETSS program and the STD program will be priority one and two. These two programs are the most similar and will most likely result in a successful integration in the grant time period. Evaluation criteria may include such things as number of non-surveillance related functions included with the program, age and life cycle of the program, overall impact the integration of the program will have on public health services, integration costs, as well as other criteria.

The project team will conduct a reverse engineering of the NETSS software to obtain a list of data elements and functionality currently available in the system. These lists or dictionaries likely represent most of the data requirements and functionality needs for the surveillance activities for communicable diseases.

The project team will initially conduct a “top to bottom” assessment of activities, procedures, methodologies and tasks of each individual in the Communicable Disease Program as it relates to surveillance responsibilities. This assessment will include ascertaining desired tasks as well as real tasks. This assessment will be conducted in enough depth to reveal data needs and functional requirements that may not be present in the data and function dictionaries described above. The identified data needs and function needs will be added to the lists, described above.

To accomplish this task, the project coordinator will initially meet with the program manager to scope out the principle program activities. Activities will be segregated into surveillance and non-surveillance activities. The Policy Workgroup will be used throughout this process to validate the activities list and segregation, provide assistance and recommend additional or desired activities. The project coordinator will then interview each staff member of that program to identify tasks and data requirements necessary to conduct the surveillance activities. Additional interview will be conducted as necessary. These interviews will incorporate scenarios and workflow diagrams and other methods, to assess processes, tasks and data needs for each activity. The Coordinator will also develop a diagram of workflow of the activities, procedures, methodologies and tasks, for each disease case through its entire reporting and investigation process. The information obtained in these interviews will be integrated into a process model. Exceptions will also be documented in the diagram. Data elements will be mapped to this diagram.

A business model that includes the workflow, use cases, functional needs and data needs for the real and desired processes will be developed and published. This model will be validated through scenario methods.

This process will be repeated for communicable disease surveillance at the local health department level. At a minimum, assessment and model development will occur for Salt Lake Valley Health Department, another urban county health department (i.e. Davis, Utah or Weber-Morgan), and one rural multi-county health department (i.e. Bear River, Central, Southeastern, or Southwest).

Following completion of the first draft Communicable Diseases model, the STD program will be modeled in the same way at both the UDOH and LHD level. Initially this model will be developed in isolation from the communicable disease model, however, before the final model is published the two models will be compared and both models adjusted as required.

The project team will then develop and publish a business model for communicable diseases. This business model will serve as the initial model for other disease processes.

Upon completion of this model the remaining programs in the first tier of programs to be integrated in the priority matrix will all be assessed through the top level. This assessment will identify the degree of similarity of those programs to the communicable diseases program. The priority matrix may be adjusted based on this assessment.

The project team will then complete all the tasks above for each program sequentially in priority. Each assessment will result in a new version of the overall business model.

5.1.c (b) Methodology:

Decision Matrix will be used to prioritize programs. UML with Rational Unified Process (Work-flow, Use Cases, etc.) and other methods will be used to document workers, activities, artifacts and overall diagram of the business model.

5.1.c (c) Deliverables:

1) Program Priority Matrix.
2) Data Dictionary for the NETSS and STD-MIS by Reverse Engineering.
3) Functional Dictionary for the NETSS and STD-MIS by Reverse Engineering.
4) Work Flow Diagrams for the Communicable Disease and STD Programs.
5) Business Model for Communicable Diseases.

5.1.d Phase IV: Internal and External Requirements Assessment:

5.1.d (a) Approach:

The NEDSS system will not be built in isolation of UDOH, state and national IT, and medical records policy. The State of Utah has a variety of statutes and rules that govern the collection of public health surveillance data and in some cases provide specific standards for data collection and storage. In addition, there are stringent legal requirements for data confidentiality, security, and accessibility. The state and UDOH have or are developing IT policies and an IT vision that

will impact the deployment of NEDSS. There are a variety of technical standards related to database development, data storage and data messaging that will need to be accommodated by the NEDSS project.

Prior to developing the strategic plan, the project team will research and conduct an assessment of all of the legal and technical standards at the federal, state, local, and private sector level and their impact on the NEDSS project. This assessment will be reported with recommendations and guidelines required to meet those obligations.

This process will be conducted with the assistance of the Policy workgroup.

5.1.d (b) Methodology:

Review statutes, rules, and policies. Prepare a matrix of requirements that will impact NEDSS. Summarize those requirements in a report, along with recommendations and guidelines necessary to insure those requirements are met.

5.1.d (c) Deliverables:

A report that includes a matrix of statutes, rules, and polices at the federal, state, local, and private sector level, a summary of the requirements of those entities, and recommendations and guidelines that ensure compliance.

5.1.e Phase V: Strategic Plan:

5.1.e (a) Approach:

This phase may occur in synchronization with Phase I. Using the standards and business model documents as guides, the NEDSS project will need to develop a strategic plan that addresses the following items:

1) The vision and goals of the NEDSS project.
2) NEDSS staff and partnerships, responsibilities, and roles.
3) Identify, prioritize, and timeline programs and systems to be integrated into the NEDSS system with enough detail to describe components of programs or systems to be integrated, the management of the remaining components post integration, and the conversion process.
4) Identify, prioritize, and timeline functions that will be incorporated into the NEDSS system.
5) Identify, prioritize, and timeline major module development and deployment.
6) Identify facilities, hardware, software, and service support that will be required by the NEDSS, and prioritize and timeline the acquisition of those components of the system.
7) Identify system maintenance, upgrade, and archive schedules.
8) Describe the expected system life and methods to expand that life.

The strategic plan will address the development and deployment of each module in the context of these eight points. It will also contain a detailed description of the decision points, timelines, and standards of success that will need to be met in the development of those modules.

This strategic plan will require UDOH executive level review and approval. However, it will not be a final document. Improvements to the plan are anticipated as opportunities, technological improvements, or other influencing factors are developed.

The NEDSS project coordinator will accomplish this phase with the assistance of the SP staff. The policy workgroup will be convened to provide guidance and assistance as necessary.

5.1.e (b) Methodology:

The Surveillance Program has $20,000 to contract some assistance to conduct this activity.

5.1.e (c) Deliverables:

A strategic plan that details priorities and timelines of system integration and infrastructure requirements needed to support that integration.

5.1.f Phase VI: IDR Analysis, Design, and Development for Communicable Diseases:

5.1.f (a) Approach:

Upon completion of the assessment and planning phases (I-V), and under authorization of the Strategic Plan, the project staff will contract with an expert to conduct analysis, design and development of the IDR to support integration of the NETSS and STD programs surveillance requirements.

This phase will be accomplished with the assistance of UDOH staff data analysts, with guidance and assistance from the technical workgroup and policy workgroup as required.

5.1.f (b) Methodology:

The methodology for this phase has not yet been determined, however, it will need to be compatible and leverage development being conducted by CDC, CDC contractors and other NEDSS states.

5.1.f (c) Deliverables:

1) The Utah Conceptual Data Model and Documents.
2) Intermediate Data Model Documents.
3) The Utah Physical Data Model.
4) The Utah IDR Physical Description Table.
5) The Utah IDR Message Table.
6) The Utah IDR.

5.1.g Phase VII: IDR Population and Validation for Communicable Disease Data:

5.1.g (a) Approach:

The project team will work with the contractor to develop methodology and schema for populating and validating the IDR. The exact requirements and methods for populating the data are not yet determined. These will be determined with the assistance of the technical workgroup and contractor. The IDR may be populated and validated for one disease entity at a time, or may be populated starting at a particular year. The historical depth of the population process could go back to 1990.

The project team will work with the technical workgroup to identify rules for validation and the validation process. This process could be parallel operation of the IDR and the legacy systems for an assessment and training period.

5.1.g (b) Methodology:

Yet to be determined.

5.1.g (c) Deliverables:

1) A protocol document for populating the IDR with historical data.
2) A populated and validated IDR.

5.1.h Phase VIII: IDR Implementation:

5.1.h (a) Approach:

The project team will coordinate with the technical workgroup, policy work group and Executive Committee to implement the IDR. The IDR will not be fully implemented until supporting infrastructure and software is in place. The minimum standards for implementation will be developed. These standards could be a set of minimum required functions.

5.1.h (b) Methodology:

To be developed.

5.1.h (c) Deliverables:

1) An Implementation Standards Document.
2) An Implemented IDR.

5.1.i Phase IX: Continuation:

5.1.i (a) Approach:

The project team will work with the Executive Committee to reassess the priorities and strategic plan and initiate work for integration of the next program and systems.

5.1.i (b) Methodology:

As described above.

5.1.i (c) Deliverables:

An expanded IDR and revised documentation.

5.1.j Phase X: Acquisition or Development and Implementation of Supporting Modules:

5.1.j (a) Approach:

As early as the development of the Strategic Plan, the project team working with the technical workgroup, and in consultation with CDC, will identify and develop requirements for the supporting modules need to secure, enter and manage data, and develop and deliver information to and from the IDR. These requirements will be included in the Strategic Plan. At this time, it is thought that these modules will be commercial-off-the-shelf products with minimal programming requirements. Through each subsequent phase, these requirements will be reviewed and adjusted. As part of the Strategic Plan, a plan to acquire the needed modules will be developed.

5.1.j (b) Methodology:

To be determined and documented in the Strategic Plan.

5.1.j (c) Deliverables:

1) A Data-Entry Data-Management Module.
2) An Analysis, Visualization and Reporting Module.
3) An (HL7) Messaging Module.
4) An XML Notification Module.
5) A Security Module including a Public Health Directory.

5.1.k Phase XI: Maintenance:

5.1.k (a) Approach:

As early as the development of the Strategic Plan, the project team working with the technical work group will identify and develop maintenance requirements for the IDR. These requirements will be included in the Strategic Plan. Through each subsequent phase, these requirements will be reviewed and adjusted. As part of the Strategic Plan, a plan to accomplish maintenance requirements will be developed.

5.1.k (b) Methodology:

To be determined and documented in the Strategic Plan.

5.1.k (c) Deliverables:

A Maintenance Plan.

5.2 Projected Schedule:

The following is a rough projection of the schedule:

	2001							2002		
Phase	May	Jun	Jul	Aug	Sep	Nov	Dec	Jan	Feb	Mar
I Organ	Hire Team	Organize Work Groups								
II IT Cap Surv	Physician Office Survey	Physician Office Survey	Hospitals and Labs	Publish Report						
III Bus Modl		NETSS Business Modeling	STD Business Modeling	Based on Program Priority Matrix						
IV Legl		Legal Influences	Publish Report							
V Devlp Plan				Develop Strategic Plan						
VI IDR Anal, Desgn, Devlp		RFI for Contractor	Select Contractor		For NETSS	For STD				
VII Popln, Validtn						For NETSS	For STD			
VIII Implmt							For NETSS	For STD	Based on Priority Matrix	
IX Contn									Based on Priority Matrix	
X Supprt Modls							Data Entry Data Management, Security, and Messaging, Reporting First			
XI Maint				Planning Docum	Continued Evaluation			For NETSS	For STD	

5.3 Project Organization:

The organizational structure of the project will consist of an Executive Committee, the Surveillance Program Staff who will serve as the NEDSS team, a Policy workgroup and a Technical workgroup.

The Executive Committee will also serve as a steering committee and will provide the decision-making and action authority to the NEDSS project. In addition, this committee will be responsible to select alternative courses of action and resolve issues. It is anticipated that the Executive Committee will need to meet with the NEDSS team weekly during phases I and II. The objectives of those meetings will be to provide guidance to the scooping process.

The two workgroups will work under the direction of and report to the Executive Committee and they will work with and provide input to the NEDSS Team. It is anticipated that the Policy Group will need to meet weekly for phases I and II. The technical group will also meet with and provide guidance to the NEDSS Team and review the work products during those phases. The technical team will meet more often during phases III, IV and V.

One or more contractors will work under the direct supervision of the NEDSS project coordinator. The project coordinator will meet with those contractors as often as is necessary to maintain acceptable progress on the project.

6 Glossary:

Access	A relational database software produced by Microsoft
ASCII	American Standard Code for Information Interchange
BT	Public Health Preparedness for Bioterrorism Cooperative Agreement (Grant)
BOE	Bureau of Epidemiology
CHARM	Child Health Advanced Records Management System. The CHARM system is a concurrent initiative within the UDOH to integrate stand-alone systems. The NEDSS project may be able to leverage with the CHARM to research and develop supporting modules and data models.
CHD	Centers for Health Data
CICS	CICS is an application server for online transaction management
CIO	Chief Information Officer
DBA	Database Analyst
dBASE	A standard database format
DELS	Division of Epidemiology and Laboratory Services
DFPM	Dept. of Family and Preventive Medicine, University of Utah School of Medicine
ELC	Epidemiology and Laboratory Capacity Cooperative Agreement (Grant)
HARS	HIV/AIDS Reporting System Software
HIPAA	Health Insurance Portability and Accountability Act (Public Law 104-191)
HIV	Human Immunodeficiency Virus
HL7	Health Level 7 Messaging Protocols and Standards
IBIS	Indicator Based Information System for Public Health will initially be a web-based static information system, where reports of summary data will be posted. Eventually, this system may develop into a dynamic system and may serve as a part of or a model for the Analysis, Visualization and Reporting Module.

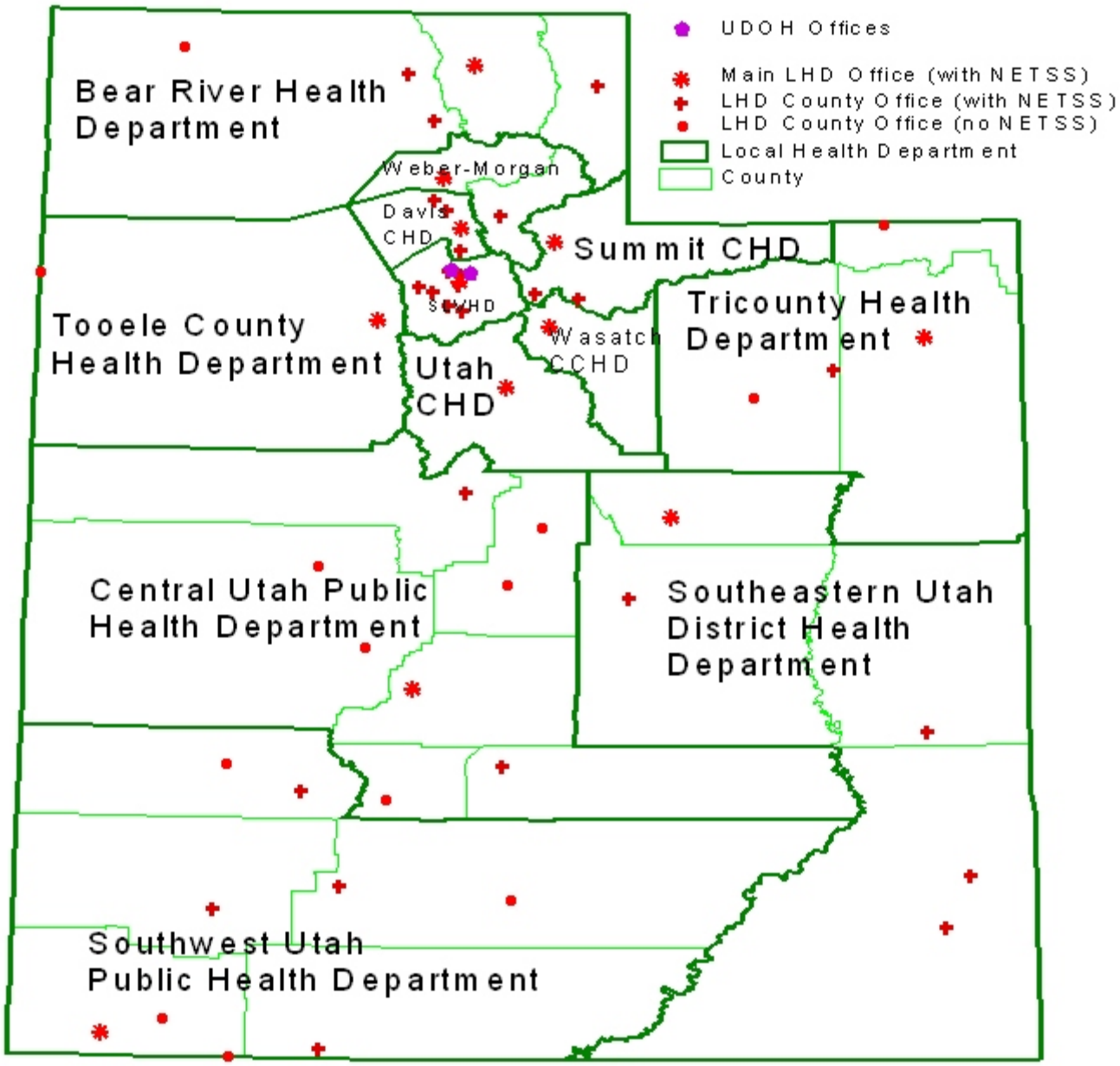
IDR	Integrated Data Repository
IHC	Intermountain Health Care (largest health management organization in Utah)
IT	Information Technology
ITS	Office of Information Technology Services, Department of Administration
LHD	Local Health Departments
LHO	Local Health Officer
NETSS	National Electronic Transmission and Surveillance System
NEDSS	National Electronic Disease surveillance System
OIT	Office of Information Technology, Utah Department of Health
PHCDM	Public Health Conceptual Data Model (Primer Edition, July 2000)
SAS	Database query, management and statistical software
SP	Surveillance Program
STD	Sexually Transmitted Diseases
STD-MIS	STD Management Information System Software
TB	Tuberculosis
TBD	To be Determined
TIMS	Tuberculosis Information Management System Software
UDOH	Utah Department of Health
UHIN	Utah Health Information Network: A private network gate, currently supporting the transmission of billing information, and planning to expand the role to include diagnostic information. The UHIN could be used as a data source as well as a model for data security and data messaging.
UML	Unified Modeling Language and Standards. This is a system that can be used to conduct both the business modeling and the database modeling requirements.
UoU	University of Utah
USIIS	Utah State Immunizations Information System and its related programs “Kids” and “Web Kids” are systems developed on the Oracle platform, before NEDSS from which the NEDSS project will be able to leverage from for security, messaging and design.
VR	Vital Records
XML	Extensible Markup Language. XML is a subset of the Standardized Generalization Markup Language (SGML) and is a Internet standard for sending, receiving and processing information over the Internet.

7 Appendices:

Appendix A. Utah Department of Health various Surveillance Programs
Appendix B. Map of Utah Local Health Departments and County Offices
Appendix C. Rules promulgated by Utah Department of Health Relating to Disease and Injury Reporting

APPENDIX A: Utah Department of Health Surveillance Programs

APPENDIX B: Map of Utah Local Health Departments and County Offices



APPENDIX C: Rules promulgated by Utah Department of Health Relating to Disease and Injury Reporting

Statutory Authorization, Requirements and Liabilities and Institutional Policy for Establishing Public Health Databases including Surveillance Databases.

Federal Code		
Reference	**Code / Title**	**Impact on the NEDSS**
Health Insurance Portability and Accountability Act (HIPAA)		
		Unknown at this time.

Utah Code Title 26: Utah Health Code		
Reference	**Code / Title**	**Impact on the NEDSS**
26-1 Department of Health Organization		
26-1-7(5)	Health data committee	Health Data Committee may have involvement in this development.
26-1-7.1	Committee procedures -- Adjudicative proceedings.	The NEDSS may need to go through the Administrative Procedures.
26-1-7.5	Health advisory council	The Executive Director may need to seek consultation from this council.
26-1-17.5	Confidential records	Most records are confidential. Immunization records can be shared with the school system, LHDs, and the Department of Human Services.
26-1-30	Powers and duties of the department	NEDSS will support: (a) promote and protect the health... (b) establish, maintain, and enforce rules... (c) investigate and control ... diseases... (d) provide for the detection, reporting, prevention, and control of communicable, infectious, acute, chronic, or any other disease or health hazard ... (e) collect and report ... on causes of injury, sickness, death, and disability and the risk factors... (f) collect, prepare, publish, and disseminate information... (k) ... investigations and inspections... (o) cooperate with the local health departments, the Department of Corrections, the Administrative Office of the Courts, the Division of Youth Corrections, and the Crime Victims Reparations Board to conduct testing for HIV infection of convicted sexual offenders and any victims of a sexual offense (p) investigate the cause of maternal and infant mortality (t) establish a uniform public health program ... of disease control, vital and health statistics, sanitation,...
26-1-30.5	Duty to establish pilot program for monitoring quality in health care.	NEDSS may be subject to this requirement.
26-2 Utah Vital Records Act		
26-2-3	Department duties and authority.	Department has authority to - Collect information on: Births, Adoptions, Marriages, and Deaths. - Conduct statistical analysis on those records - Create reporting districts
26-2-4	Content and form of certificates and reports	Vital records subject to national standards, require a “date filing” field.
26-3 Health Statistics		
26-3-2	Powers of department to collect and maintain health data.	Department can collect voluntary data and required data on: - illness and disability - determinants of health and health hazards - health resources - utilization of health care - costs and financing - other health or health-related matters
26-3-4	Quality and publication of statistics.	NEDSS algorithms must be error free.
26-3-5	Coordination of health data collection activities.	NEDSS must be coordinated with other data collection activities.

26-3-6	Uniform standards -- Duties of department.	NEDSS must meet department data standards.
26-3-10	Department measures to protect security of health data.	NEDSS must meet these security requirements of: - limited access - have a designated physical security manager - have a system for monitoring security - a way of removing identifiable data from the database.
26-5 Chronic Disease Control		
26-5-3	System for detecting and monitoring diseases established by department.	Department has authority to collect information on chronic diseases such as cancer, diabetes, cardiovascular and pulmonary diseases, and genetic diseases.
26-6 Utah Communicable Disease Control Act		
26-6-3	Authority to investigate and control epidemic infections and communicable disease.	Department has authority to investigate and control epidemics infections and communicable disease. Department shall provide for the detection, reporting, prevention, and control of communicable diseases and epidemic infections or any other health hazard which may affect the public health.
26-6-3.5	Reporting AIDS and HIV infection -- Anonymous testing.	Allows for: - keeping records on contacts for HIV/AIDS - keeping records on anonymous testing
26-6-6	Duty to report individual suspected of having communicable disease.	Defines reporting agencies NEDSS will have to be accessible to: - health care providers - health care facilities - mental health facilities - nursing homes and other care facilities - dispensaries - clinics - laboratories - individuals who have knowledge - schools - child care programs
26-6-7	Designation of communicable diseases by department -- Establishment of rules for detection, reporting, investigation, prevention, and control.	Department has authority to designate which diseases will be reportable and tracked by NEDSS.
26-6-27	Information regarding communicable or reportable disease confidential -- Exceptions.	NEDSS will need to protect communicable disease data.
26-6-30	Exclusions from confidentiality requirements.	NEDSS will need to accommodate this requirement.
26-6a Disease Testing and Workers' Compensation Presumption for Benefit of Emergency Medical Services Providers		
26-6a-5	Reporting of test results.	Test results reported to the department.
26-6a-6	Confidentiality of information concerning test results -- Exceptions.	NEDSS will need to protect this data.
26-7 Health Promotion and Risk Reduction		
26-7-1	Identification of major risk factors by department -- Education of public -- Establishment of programs.	NEDSS must support the identification of risk factors contributing to injury, sickness, death, and disability and the identification of public health needs.
26-8a Utah Emergency Medical Services System Act		
26-8a-203	Data collection	Department authorized to collect information about emergency medical services.
26-8a-253	Statewide trauma registry and quality assurance program.	Department authorized to establish a statewide trauma registry and to report on data collected in that registry.
26-10 Family Health Services		
26-10-6	Testing of newborn infants.	Department to establish a newborn screening program for metabolites and hearing loss.
26-10a Healthy Communities Program Act		
26-10a-102	Healthy Communities Program -- Creation -- Description --Committee.	Department will track the activities of this program.
26-18 Medical Assistance Act		
26-18-104	Confidentiality of records.	Medicaid records protected.

26-25 Confidential Information Release		
26-25-1	Authority to provide data on treatment and condition of persons to designated agencies -- Immunity from liability.	NEDSS must comply with these requirements.
26-25-3	Information considered privileged communications.	Data in NEDSS is protected.
26-25-5	Violation of chapter a misdemeanor -- Civil liability.	Liability for breach of confidentiality.
26-30 Rights and Privileges of Blind and Disabled Persons		
26-30-1	Physically disabled persons' rights and privileges.	NEDSS must be accessible to the visually impaired.
26-33a Utah Health Data Authority Act		
26-33a-104	Purpose, powers, and duties of the committee.	Health Data Committee is established and directs state health care data collection activities, including what data is to be collected and how the is data validated.

Utah Administrative Rules

Reference	Rule / Title	Impact on the NEDSS
R380 Administration		
R380-20	Government Records Access and Management.	Certain department records (OME, Vital Records) may be assessable through GRAMA (Utah Code 63-2).
R380-25	Submission of Data Through an Electronic Data Interchange	Allows department to collect information electronically.
R384 Community and Family Health Services, Chronic Disease.		
R384-100	Cancer Reporting Rule	Cancers are reportable to the Utah Cancer Registry.
R386 Community Health Services, Epidemiology.		
R386-702	Communicable Disease Rule.	
R386-703	Injury Reporting Rule.	
R386-800	Immunization Coordination.	
R388 Health, Epidemiology and Laboratory Services; HIV/AIDS, Tuberculosis Control/Refugee Health.		
R388-803	HIV Test Reporting.	Establishes the reporting requirements for HIV/AIDS.
R388-804	Special Measures for the Control of Tuberculosis.	Establishes the reporting requirements for Tuberculosis.
R398 Health, Community and Family Health Services, Children with Special Health Care Needs.		
R398-1	Newborn Screening.	Authorization for the department to maintain records of newborn screening.
R398-2	Newborn Hearing Screening.	Authorizes the department to collect data on newborn hearing screening.
R402 Health, Community and Family Health Services, Health Education Services		
R402-5	Birth Defects Reporting.	Establishes reporting requirements for birth defects.
R406 Health, Community and Family Health Services, WIC Services.		
R406-100	Special Supplemental Nutrition Program for Women, Infants and Children.	Requires the department to keep and maintain WIC eligibility records.
Title R414 Health, Health Care Financing, Coverage and Reimbursement Policy.		
R414-308	Record Management.	Describes requirements for MEDICAID records.
R414-32	Hospital Record-keeping Policy.	Describes requirements for MEDICAID records.
R426 Health, Health Systems Improvement, Emergency Medical Services.		
R426-5	Hospital Trauma Categorization Standards.	Authority and reporting requirements for the Hospital Trauma Registry.
R428 Health, Center for Health Data, Health Care Statistics.		
R428-2	Health Data Authority Standards for Health Data.	Standards for health data.
R428-5	Appeal and Adjudicative Proceedings.	
R428-10	Health Data Authority Hospital Inpatient Reporting Rule.	
R428-11	Health Data Authority Ambulatory Surgical Data Reporting Rule.	

R428-12	Health Data Authority Survey of Enrollees in Health Maintenance Organizations.	
R428-20	Health Data Authority Request for Health Data Information.	
R436 Health, Center for Health Data, Vital Records and Statistics.		
R436-1	Duties of the Department of Health.	
R436-2	Infants of Unknown Parentage; Foundling Registration.	
R436-3	Amendment of Vital Records.	
R436-7	Death Registration.	
R436-9	Persons and Institutions Required to Keep Monthly Listings of Vital Statistics Events.	
R436-10	Birth and Death Certificates.	
R436-13	Disclosure of Records.	
R448 Health, Medical Examiner.		
R448-10	Unattended Death and Reporting Requirements.	Requirement to report unintended deaths.

Utah Department of Health Policy		
Reference	**Code / Title**	**Impact on the NEDSS**
07-01	Data Stewardship within the Utah Department of Health	
07-02	Policy for Coordinating New Data Requests with Existing Data Systems	